A study of the role of the patient advocate as 'a social support structure', in HIV/AIDS medication adherence, in Dimbaza and Zwelitsha Clinics in the Province of the Eastern Cape, South Africa.

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DECLARATION

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Abstract

The purpose of the study was to examine the impact of the community adherence counsellors or patient advocates (PAs) on antiretroviral medication adherence as a form of social support. In the battle against HIV/AIDS patient advocates have been used to do basic psychosocial assessment and to document the patients' social issues, focusing on factors which might have an impact on the patients' adherence. This is to evaluate issues that might impact on long-term adherence. In many cases it may be necessary to do a home visit. The research sought to identify the existing social support structures available in the clinic and the patients' perceptions of such support. It is also important to identify whether there are any discrepancies on the social support given, based on the patients' perceptions.

The study sample included Xhosa and English speaking individuals over the age of 18 years receiving treatment for HIV/AIDS. The study participants were recruited at two out-patients settings in Dimbaza and Zwelitsha, Eastern Cape Province, South Africa. A descriptive, exploratory, cross sectional design was utilized to explore the nature of the relationship among social support and other selected variables including socio-demographic variables and quality of life.

Participants reported being fairly satisfied with the quality of support they received. Emotional support and often instrumental support were most desired. The support they received helps people with HIV/AIDS to manage uncertainty. The provision of instrumental support facilitated skills development. Adherence counselling tasks can be shifted to lay cadres like patient advocates without compromising the quality of counselling. Patient advocacy within the community is necessary to improve retention of clients on antiretroviral therapy.

OPSOMMING

Die doel van die studie was om die impak van die gemeenskap nakomings raadgewers of pasiënt advokate (PAs) op antiretrovirale nakoming as ‘n vorm van sosiale ondersteuning te ondersoek. In die stryd teen MIV/VIGS is pasiënt advokate reeds gebruik om basiese psigo-sosiale evaluering te doen en om die pasiënte se sosiale kwessies te dokumenteer, en om te fokus op faktore wat ‘n impak het op nakoming kan hê. Dus om op kwessies te fokus wat 'n impak op langterm nakoming kan hê. In vele gevalle kan dit dalk noodsaaklik wees om ‘n huisbesoek te doen. Die navorsing het gepoog om die bestaande sosiale steunstrukture binne die kliniek te identifiseer asook die pasiënte se persepsies daarvan. Dit is ook belangrik om uit te vind of daar enige wanverhoudings met betrekking tot sosiale ondersteuning is, volgens die pasiënte se persepsies.

Die studie steekproef het Xhosa en Engelssprekende individuë bo 18 jaar ingesluit wie behandeling vir MIV/VIGS ontvang. Die deelnemers is by twee buitepasiënte terreine in Dimbaza en Zwelitsha, Oos-kaap provinsie, gewerf. ‘n Beskrywende, nasporings, deursnee-ontwerp is gebruik om die aard van die verhouding onder gemeenskapsondersteuning en ander veranderlikes, insluitend sosio-demografiese veranderlikes en lewenskwaliteit, te ondersoek.

Deelneemers was taamlik tevrede met die kwaliteit van die ondersteuning wat hulle gekry het. Emosionele ondersteuning, en dikwels instrumentele ondersteuning, was mees begeer. Die ondersteuning wat hulle gekry het help mense met MIV/VIGS om onsekerheid te bestuur. Die voorsiening van instrumentele ondersteuning het die ontwikkeling van vaardighede vergemaklik. Nakomingsraadgewing take kan vir gewone persone soos pasiënte advokate gegee word sonder om die kwaliteit van die raadgewing negatief te affekteer nie. Pasiënte advoksie in die gemeenskap is noodsaklik om die retensie van kliënte op antiretroviral terapie te verbeter.

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CHAPTER 1: Introduction

1.1. BACKGROUND

South Africa has one of the worst HIV/AIDS epidemics in the world. It is estimated that more than 1700 people are infected each day and that there are a total of 5,4 million South Africans infected (UNAIDS, 2007). Of the total number of people living with HIV (ages 15-49), an estimated 2,7 million are women and more than 250,000 are children (ages 0-14) (Department of Health, 2007).

Projections suggest that without comprehensive treatment interventions, the mortality rate attributable to HIV/AIDS is likely to reach 800,000 deaths per year by 2010 (Dorrington, 2002).

The World Health Organisation (2007) estimates that 460 000 people in South Africa received treatment at the end of 2007 equating it to 28% of those in need of treatment.

Since the introduction of antiretroviral medication, the improvements in treatment options and introduction of Highly Active Antiretroviral Therapy (HAART), HIV has now become a chronic illness instead of an acute terminal illness. Continuous viral suppression which is a primary goal of medical management of HIV infection, results in longer and healthier lives for HIV-positive individuals (Ferguson et al 2002).

It is therefore important that a strict lifestyle, and long treatment adherence to drug regimens is essential to sustain health benefits and to minimize drug resistance associated with treatment failure. Success of antiretroviral therapy (ART) thus requires not just medical attention but long term social and psychological support, including monitoring adherence (Beals et al, 2006). Resistance to ART therapy can develop very easily if doses are missed, and studies have shown that patients need to take at least 95% of doses in order to have a good chance of maintaining viral suppression. The success of ART partly depends on patients' level of adherence.

Good adherence to antiretroviral therapy decreases viral load, increases CD4 count and there are decreased opportunistic infections and side effects (Santrock, 2007). The commitment of

the patient has been shown to be strengthened by careful counselling of both patients and his or her family before the start of therapy. The ongoing support from the health providers as well as community support is very important. The work that is done by health workers is of paramount importance in ART adherence. On the basis of the evidence by Igumbor et al, (2007), the integrated community-based adherence support is important to ensure that patients remain in care, are virologically suppressed and regularly pick up their treatment from ART clinics.

A community based adherence support programme through patient advocates (PA) was designed to complement the clinic-based ART services to ensure that patients are optimally adherent to treatment. The patient advocate support service is provided by Khethimpilo, a non-governmental organisation in Cape Town, South Africa, that focuses on providing holistic support to ARV patients and their families. The focus is on early recognition of barriers to adherence and encouragement of voluntary counselling and testing (Igumbor et al, 2007).

There are few comparable studies about medication adherence and health behaviour. Research on the characteristics of the patient advocates and patients, and their interpersonal relationships in HAART adherence would contribute greatly to understanding of effective adherence intervention models for this population.

Informal care-giving and social influence theories suggest that taking advantage of existing supportive relationships may lead to sustained positive changes in adherence behaviour (Knowlton, 2003). It is therefore essential to determine what effective support means for those on HAART and to understand the barriers, material and social, that decrease adherence.

In the study the aim is to investigate patient and provider perceptions about support strategies that would encourage the highest rates of HAART adherence. The goal was to gather information from patients and health care providers involved in HAART programs to determine the characteristics of effective treatment support and to learn more about social and material barriers to HAART.

It is important therefore to understand the impact the patient advocates have on the medication compliance through their social support.

1.2. OBJECTIVES OF THE STUDY

- To identify the existing social support structures available in the clinics.
- To identify the patient's perceptions of their social support structures.
- To identify discrepancies in the social support structures based on patient's perceptions.
- To provide guidelines and possible interventions to improve support structures.

1.3. RESEARCH QUESTION.

What is the relationship between the levels of support given by patient advocates or community based adherence workers and adherence to ARV treatment?

1.4. SIGNIFICANCE OF THE STUDY

The main aim of the study was to identify the relationship between the social support given by patient advocates and ART adherence. This will be done by way of examining the extent to which health workers play a role in ART adherence in Dimbaza and Zwelitsha in the Eastern Cape, South Africa.

The challenges facing the health system in South Africa are likely to impact on life-long adherence for patients in the context roll of ART. The findings in several studies conducted on social support from family, friends and support groups in relation to ART are critical of adherence. It is important therefore to determine if the existing social support structure are having any significance in ART adherence.

CHAPTER 2: Literature Review

In the study by Ware et al, 2009, an ethnographic study was conducted to investigate why ART adherence is high in Sub-Saharan Africa. The study was done in Nigeria, Tanzania and Uganda. The study was undertaken because there was indication that people living with HIV/AIDS in Sub-Saharan Africa generally took more than 90% of their prescribed doses of ART. This was a better level than in North America. To determine how patients were able to achieve these levels, patients were asked about their experiences of ART and the type of help they receive from their treatment partners. The findings were that patients and the treatment partners tended to overcome economic obstacles to ART adherence. Patients borrowed or begged money from people to pay for travelling to the clinics. This was done as they wanted to prioritize their treatment adherence. The researcher findings were that the prioritization of adherence to ART reflects the importance of relationships as a resource for managing economic hardship. ART adherence was also a way of making sure that patients were taking responsibility for their lives and that of their families. Patients in turn by adhering to their treatment were promoting good will from their helpers and thus ensuring their continuing help. In the study the role played by the treatment supporter became evident in ART adherence.

Maintaining good adherence among patients requires vigilance on the part of health care workers. It is therefore evident that as time progresses, there are fewer adherences, thus monitoring and ongoing support of adherence is essential (The South Africa National Antiretroviral Treatment Guidelines, 2004).

Margaret Spies, submitted a thesis as partial fulfilment of the requirement for her Degree Doctor Philosophiae in Social Work with the University of Pretoria, and some of her findings were that the impact that the various psychosocial needs of millions of HIV/AIDS people living on ART will tax the available professional social services particularly the social work profession. As a result of these findings it has been possible to use other health workers to do psychosocial counselling (Spies, 2001). It is important therefore to understand what adherence to treatment means and what social support means.

Antiretroviral adherence is the second strongest predictor of progression to AIDS and death after CD4. Incomplete adherence to ART however is common in all groups of treated individuals. The average rate of adherence to ART is approximately 70% despite the fact that long term viral suppression requires near prefect adherence (Fomundam, 2008).

2.1. DEFINITION OF ADHERENCE TO TREATMENT

Adherence may be defined in many different ways but the extent to which a client's behaviour coincides with prescribed regimen as agreed upon through a shared decision-making process between client and the health care provider. The patient takes an active part in this collaborative process by understanding and implementing the treatment plan.

Adherence unlike drug therapy cannot be defined as a single method with a defined prescription or formula but is a result of a complex interaction between the patient, a prescribed medication and the health system (Garcia, Schooley & Badaro, 2003).

2.2. WHAT IS SOCIAL SUPPORT?

Social support is defined as network of family, friends, neighbours and community members that is available in times of need to give psychological, physical and financial help and this also includes the health care providers (Tengpe, 2005).

Patients' adherence to treatment is a crucial issue for the long-term success of antiretroviral therapies. Psychosocial factors play an important role as determinants of non-adherence. Patient adherence includes taking medications, keeping appointments, undertaking recommended preventive measures such as dieting, exercise, substance use and changing possibly deep-seated behavioural patterns (Fomundam, 2008).

The bio psychosocial model is the general model of approach that includes biological, psychological and social factors and all play an important role in human functioning in the context of disease or illness. Health is best understood in terms of a combination of biological and social factors rather than purely in biological terms (Santrock, 2007).

Several psychosocial problems influence adherence to antiretroviral treatment of HIV/AIDS, the relationship between care providers and patient, some disease characteristics, the treatment regimen and therapeutic context.

Becoming HIV infected often means living under difficult situations, as many lose their jobs and friends. On top of all that abandonment of life projects, stigmatisation becomes a reality. To regain health and quality of life, it is fairly easy when following the right antiretroviral therapy, to find good health means maximal and durable undetectable level of viral load and the steady increase of CD 4 cells. In many people with HIV/AIDS quality of life means having a job, being reintegrated in different social groups and being accepted and loved as any other human being. The medical intervention is to provide medical support and give antiretroviral and also provide psychosocial support (Tengpe, 2005).

In the study conducted in Thailand there was awareness that augmenting adherence through treatment supporters is one of the promising strategies (Knodel et al, 2010). In their study the role of parents and family members in ART treatment became evident. The study was conducted through self administered questionnaires given to ART patients when they came for resupply at 18 hospitals sites in 5 provinces in Bangkok. This study had important findings in that family members are part of the treatment support programs but receive less attention than their children's peer. They find that parents are highly motivated to ensure the health of their adult children and often live with or near their adult children. Health professionals often assume that older persons who often have low levels of education especially in poorer countries are incapable of sufficiently understanding ART to provide useful assistance. Despite the little education parents exhibited considerable understanding of ART and strong motivation to ensure proper adherence by their HIV infected adult children (Williams et al, 2008).

The use of highly active antiretroviral therapy, (HAART) has changed the landscape of human immunodeficiency virus infection and AIDS. Patients are not only living longer, but are leading relatively healthier lives. To have this stable lifestyle, people using HAART need to maintain a high adherence rate. The maintenance of high adherence is a new challenge to clinicians and service providers. Despite the good adherence, missing a dose in highly adherent HIV patients is probably the result of the interaction between multitudes of factors. Results of a study conducted in China with high adherence rates to HAART in a cohort of Chinese male HIV/AIDS patients concluded that the support of the patient, family, spouse and friends may be important, though a statistical significance association could not be established (Lee, Ma, Chu & Wong, 2007).

Mellins et al, (2004) in their study examined child psychosocial and caregivers or family factors influencing adherence to ART in peri-natal human immunodeficiency infected children. Families in which the caregiver or child reported missed doses (no adherence) were compared with families who reported no missed doses (adherence). The findings were that efforts to improve children's adherence to complex antiretroviral regimens requires addressing developmental, psychosocial and family factors. Psychological emotions like anger also have an impact on adherence.

The relationship between psychological variables and medication adherence is still poorly understood. A better understanding of the psychological determinants of compliance might allow for the identification of patients who are at higher risk of non-adherence. To sustain adherence to HAART, these patients may benefit from increased clinical attention or intervention (Leombruni, Fassiono et al, 2009).

Psychosocial support assists with disclosure and improvement of the quality of life. This is what has happened in Mother 2 Mothers, a mentorship program in Cape Town, South Africa, for pregnant women and mothers with infants. They are engaged by mentor-mothers who share personal experiences with them, encourage enrolment in Prevention of Mother to Child Transmission (PMTCT) programs and adherence to PMTCT interventions (Aunt, Besser & Mbono, 2006).

Grandmothers against Poverty and AIDS (GAPA) a support group in Khayelitsha, Western Cape, South Africa, has acknowledged that a problem shared became less of a problem and resolved to encourage families to disclose their HIV status so that they too could benefit from community support (Brodrick & Mafuya, 2005).

The relationship between the clinician and the patient must accommodate the needs for ongoing education, respect and support required in demanding regimens like ART treatment. The clinician should restrain his or her enthusiasm to commence therapy and allay the patient's anxiety until both are prepared to meet the adherence needs of the subsequent regimen (Andrews, 2002).

Spies (2007) in her studies confirmed the importance of social support in high levels of unemployment, and in couples with families headed by women who receive little support, lead to almost total dependency on social security.

The use of social support services depends on awareness, availability, accessibility and the level of stigma and disclosure of HIV status. Disclosure of HIV is perceived to be an important factor in enabling HIV positive individual to seek and utilize services and receive necessary support. The results showed that respondents had preferences in terms of who they disclosed to, and that family member were a critical source of social support, providing particularly emotional support (Williams, 2007).

CHAPTER 3: Methodology

3.1. INTRODUCTION

The purpose of this research was to explore the role played by patient advocates as a social support structure in the clinical and social support structure in HIV/AIDS medication adherence. This chapter describes the research design and method of research used. The study adopted quantitative and qualitative research approaches because of the nature of the topic. Data was collected from patients and health care workers using a questionnaire and a semi-structured interview schedule for qualitative approach.

3.2 RESEARCH DESIGN

The study took place in the Dimbaza Community Health Centre and Zwelitsha clinic in King William's Town in the Eastern Cape, South Africa. Dimbaza ARV unit is occupying offices inside the health centre and which is currently following more than 800 patients on ART. Zwelitsha ARV unit has a prefabricated structure outside the main building of the clinic and has been following referred patients from Bisho Hospital, but since October 2010 has been accredited to initiate patients on ART.

3.3. STUDY SITES

The two sites Zwelitsha clinic and Dimbaza Community Health Centre were selected based on patient enrolment on ART and patient advocate coverage. The study targeted patients who were on ART for three months and longer.

3.4. SAMPLING

Patients and health care providers were part of the sample.

Criteria for inclusion in the study were:

1. All patients, male or female who were on ART and were age 18 years or older.
2. All those patients who were prescribed antiretroviral therapy for HIV/AIDS for not fewer than 3 months and up to 24 months at the time of sampling.
3. All patients residing in Dimbaza and Zwelitsha and surrounding villages and receiving care and treatment at Dimbaza Community HealthCare Centre and Zwelitsha Clinic.

Health care providers were volunteers who were given invitation letters to participate.

Various sampling techniques were employed for the research groups. A sample of 40 respondents was selected by way of the probability simple random sampling technique for the quantitative research. These were patients attending ARV clinic at Dimbaza Community Health Center and Zwelitsha clinic. Ten Health Care Workers were invited to take part in the qualitative study.

3.5. RECRUITMENT

Patient participants were recruited at the clinic during routine follow-up visits and were sampled from the total population of patients, male or female, of all races and socio-economic group who were HIV-positive. Health care providers were contacted from the response received and through the invitation given.

3.6. DATA COLLECTION PROCES

Data was collected through qualitative and quantitative methods. In a quantitative method the researcher selected a questionnaire as a data collection instrument because it offers anonymity and increases the likelihood of obtaining accurate information (Ary, Jacobs & Razaviah 1999: 423). Data collection of both paradigms was employed; semi-structured interviews with an interview schedule for the qualitative data collection method. Written notes were used to collect data. A structured questionnaire was used for the quantitative data collection.

The qualitative method involved the use of semi-structured open-ended questions that investigated personal experience form the subjective perspective of each respondent about ART. At each facility the researcher conducted semi-structured interviews with one pharmacist, two patient advocates and two nurses. This was done to establish the health workers' perspective on the challenges of non-adherence and the existing social support structures in the two sites. The interviews were semi-structured meaning that pre-designated core topics, but not specific questions were covered. The respondents to the quantitative study were asked to complete the structured questionnaire after providing their informed consent. The research was conducted during November and December 2010. The questionnaire was self-administered but the researcher had individual and personal contact with each respondent and assisted with the filling of the questionnaire. Patient participant interviews were conducted at home or a place outside the clinic. Health provider interviews took place at the clinic. Privacy was protected by conducting the interviews in locations

where the conversation could not be overheard. The interviews were conducted in the local language which is Xhosa and also in English. Written notes were used to collect data.

3.7. DATA ANALYSIS

The data was analysed by using frequencies and basic correlation and manual master sheet.

Chapter 4: Data Analysis and Findings

4.1. INTRODUCTION

Data analysis is a process of bringing order; structure and interpretation to the mass of data collected and should include examining, categorizing, tabulating or otherwise recombining the evidence in order to address the research problem (Devos, Fouche & Venter, 2002: 224). The findings are presented using the objectives of the study. Findings from the questionnaire are presented together with the qualitative findings from the interview schedule.

The quantitative data will be presented in percentages and frequencies and by means of tables and graphs according to the various subsections in the questionnaire. The qualitative data will be presented using themes and sub-themes. All the interviews were transcribed verbatim and analysed by using manual master sheet.

4.2. DEMOGRAPHIC INFORMATION OF PARTICIPANTS ACCORDING TO THE QUESTIONS.

TABLE 1. Characteristics of respondents combined on both clinics(n = 37)

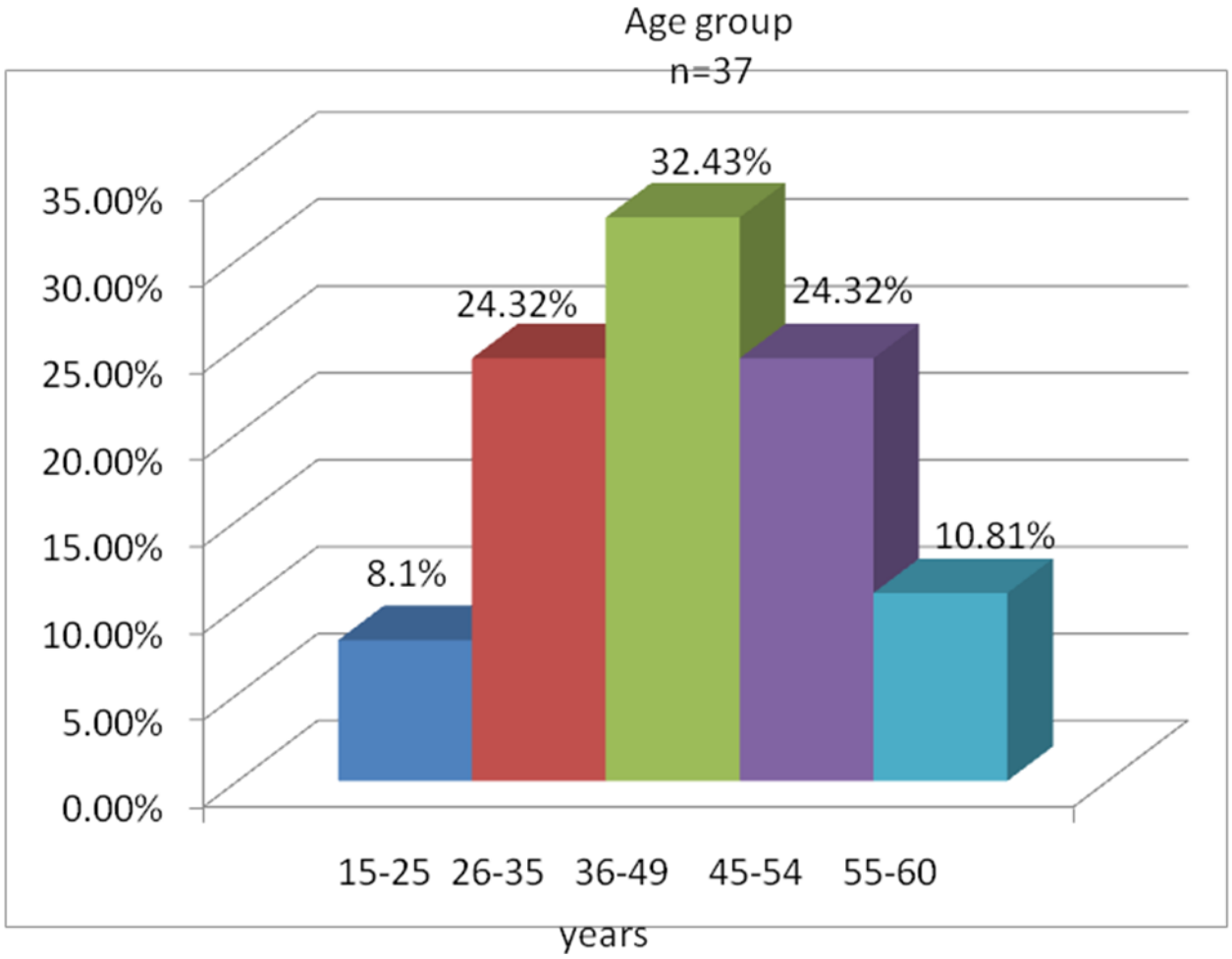
Characteristics	**number**		
Age in years		**Employment status**	**number**
15 – 25	3	Unemployed	27
26 - 35	9	Employed	10
36 – 49	16		
50 - 54	4		
55 - 60	4		
Sex			
Male	15		
Female	22		
Marital status			
Single	13		
Married	17		
Divorced	4		
Widowed	2		
Cohabitating	1		
Educational status			
Grade 11 or below	26		
Grade 12 & Post matric	11		
Residential area			
Urban	28		
Rural	9		

4.2.1 Age distribution

The socio-demographic profiles of respondents are described above. These include, age, gender, educational level, and residential area.

Forty questionnaires were distributed among two clinics with each clinic receiving twenty questionnaires. The response rate per clinics was as follows; Dimbaza clinic was 17 (85%), Zwelitsha Clinic was 20 (100%). The overall response rate was 37 (92,5%) which was high taking into account that response rates for questionnaires can be low because of the nature and process of self administered questionnaires. Respondents' ages were categorized into 5 groups, 15-25; 26-35; 36-49; 50-54; 55-60 and above. Age distribution is shown in Figure 2.

Figure1: Age Distribution



The above graph illustrates the following:

3 (8,1%) of the respondents were between 15-25 years

9 (24,32%) of the respondents were between 26-35

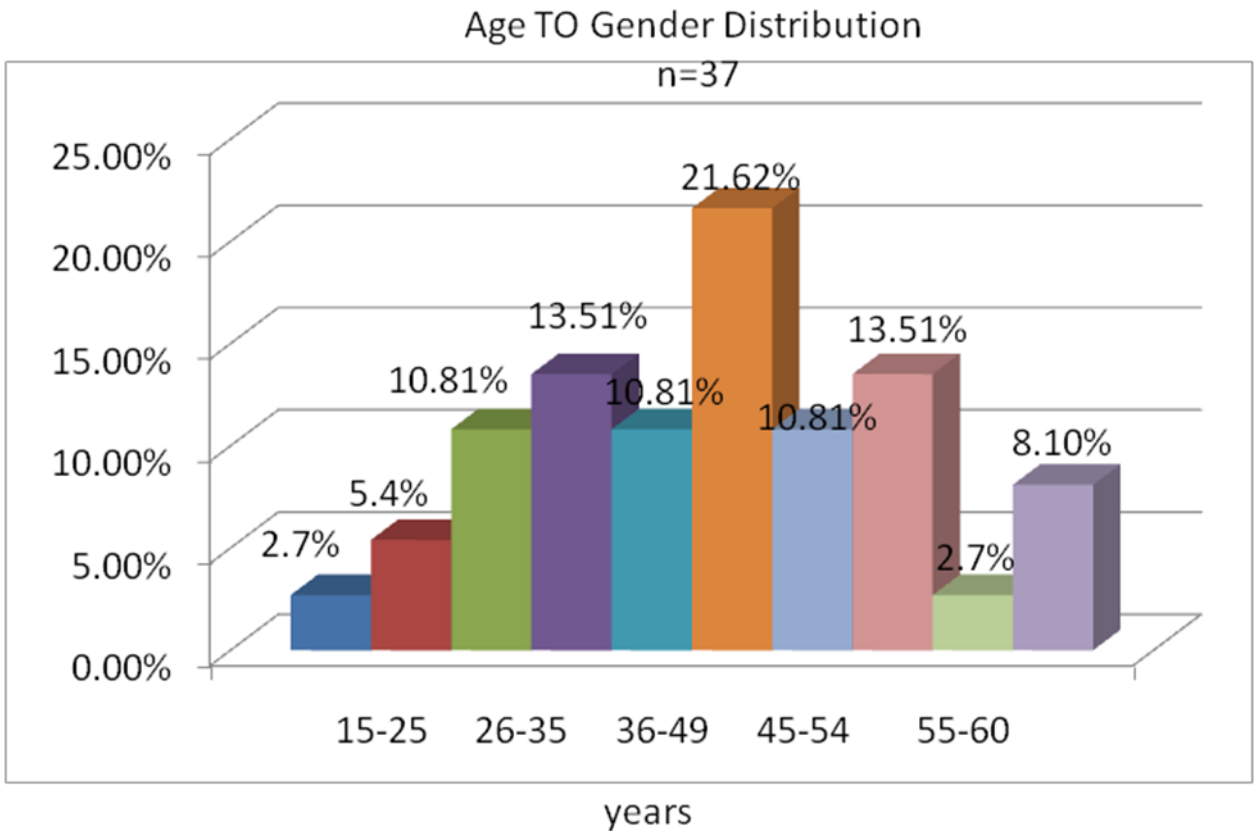
12 (32,43%) of the respondents were between 36-49

9 (24,32%) of the respondents were between 50-54

4 (10,81%) of the respondents were between 55-60)

The combined age distribution for both clinics indicated that the majority of respondents 12 (32,3%) fell between the ages 36-49 years which was slightly significant.

Figure 2: Age to gender distribution



2,7% of the male respondents were between 15- 25

5,4% of the female respondents were between 15- 25

10,81% of the male respondents were between 26- 35

13,51 % of the female respondents were between 26- 35

10,81% of the male respondents were between 36- 49

21,62% of the female respondents were between 36- 49

10,81% of the male respondents were between 50, 54

13,51% of the female respondents were between 50, 54

2,7% of the male respondents were between 55- 60

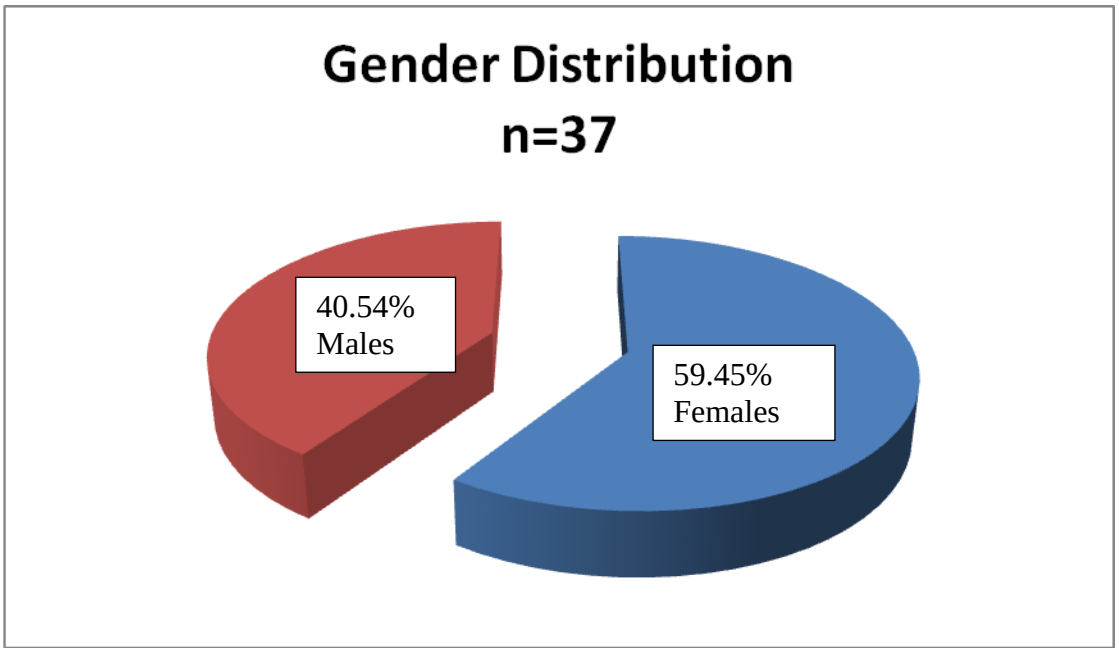
8,10% of the female respondents were between 55- 60

It is evident from this research that the majority of respondents 12 (32%) fell in the age group of under 50 years. Of this 12 (22%) respondents were women. This research has further revealed that 9 (24%) of respondents were under the age of 35.

4.2.2. Gender of respondents

The majority of respondents were female patients, 22 (59%) while male patients who responded were 15 (40,5%). More females than males are being infected by HIV/AIDS; 5,4 million South Africans sre infected, an estimated 2,7 million infected are women (UNAIDS, 2007). The findings also correlate with the National HIV and Syphillis antenatal sero-prevalence survey in South Africa (2004:1), where the number of women with HIV infection attending the antenatal clinics is greater among women in their late twenties and lower among teenagers. The risk of HIV infection increases with age (22%) indicating a higher risk among the older teenagers and women in their early twenties. Age may influence adherence, studies found that, with the exception of the most elderly, adherence increases with age (Jones et al, 1999).

Figure 3: Gender distribution



4.2.3. The findings related to the relationship between marital status, education, residential area and living condition in relation to ART adherence.

The research findings of the quantitative research reveals that 24 (65%) of respondents have grade 11 or below in level of education, whilst 9 (24%) have grade 12, or matric certificates and post matric or diploma are 3 (8%).

Table 2: Level of education

Educational Status	**Combined n=37**	**Zwelitsha n=20**	**Dimbaza n=17**
Grade 11 or below	24 (65%)	10 (50%)	14 (82%)
Grade 12	9 (24%)	7 (35%)	2 (12%)
Post matric	4 (11%)	3 (15%)	1 (6%)
Total	**37**	**20**	**17**

Table 3: Residential area

Residential area	**Combined n=37**	**Zwelitsha n=20**	**Dimbaza n=17**
Rural	9 (24%)	4 (20%)	5 (29%)
Urban	28 (76%)	16 (80%)	12 ((71%)
Total	**37**	**20 (100%)**	**37 (100%)**

Table 4: Marital status

Marital status	**Combined n=37**	**Zwelitsha n=20**	**Dimbaza n=17**
Single	13 (35%)	7 (35%)	6 (35%)
Married	17 (46%)	9 (45%)	8 (47%)
Divorced	4 (11%)	2 (10%)	2 (12%)
Widowed	2 (5%)	1 (5%)	1 (6%)
Cohabitating	1 (3%)	1 (5%)	0
Total	**37**	**20 (100%)**	**17 (100%)**

From the data collected for the qualitative element of the study regarding the relationship between marital statuses, educational status, residential area or living condition in relation to ART adherence, these sub-themes emerge:

- Disclosure in married couples affects medication adherence,
- Educated people, or married couples are supportive to partners,

- Financial difficulties and material needs do influence medication adherence.

Table 5: Marital and educational status, residential area and living condition influences adherence to treatment

Respondent	Verbatim interview quote from the research interview
Professional Nurse 1	"If a married couple has not disclosed to each other, adherence is going to be poor".
Professional Nurse 2	"Level of education is going to affect adherence in terms of taking treatment timeously and correctly".
Patient Facilitator	"Logistics such as transport and money to collect treatment if staying far from ARV site".
Patient Advocate	" Residential, or living condition sometimes has a negative impact on adherence"

The above research findings are supported by the following literature:

Level of education

A lower level of general education and poor literacy may impact negatively on some patients' ability to adhere, while higher level of education has a positive impact (Catz et al, 1999). Knowledge and understanding of HIV disease has a profound effect on optimal adherence.

Financial constraints

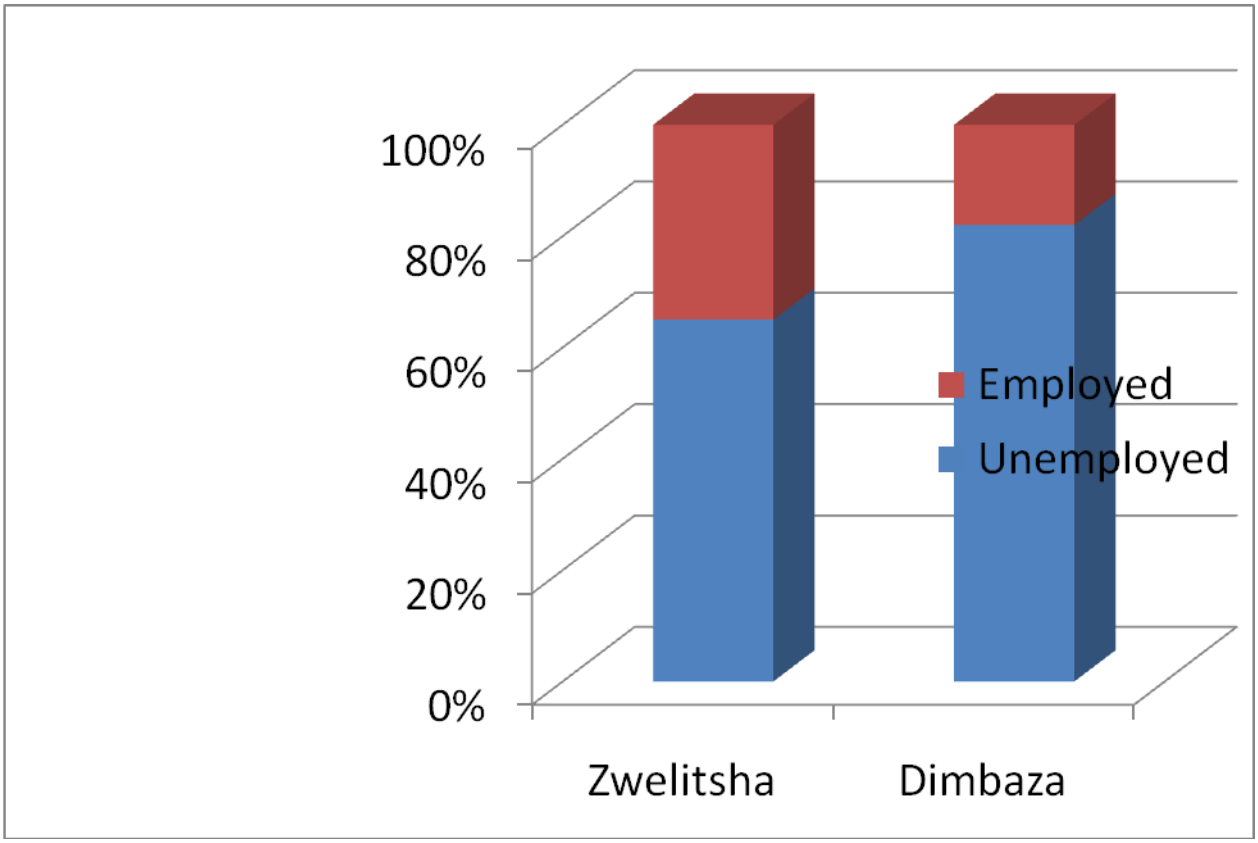
Studies conducted in Africa reveal that the cost of medication is one of the most significant barriers to treatment adherence. In Botswana (Weiser et al, 2003) report adherence difficulties related to the financial demands of therapy and an inability to afford medicines for varying periods. In resource-poor countries many people live below the poverty line and there is often no medical insurance or disability pension for people living with HIV (Katabira, 2002).

Social and economic factors may combine to yield poor adherence outcomes. Poverty in itself is likely to affect adherence, as financial resources may need to be directed elsewhere, funds for travel to the ART clinic may not be available, and child-care may not be readily be accessible for parents who attend clinic visits. The competing demands of several

responsibilities such as work and family life, along with the stresses associated with poverty and difficult life circumstances such as unemployment, may obviate an acknowledgement of the importance of complying with treatment regimens in general (Simoni et al, 2002). In addition, food required to be taken alongside medication may not be easily affordable and money for external aids and support such as alarms and diaries may not be available. Figure 4 below illustrate the employment status of respondents and its economic impact.

The expression of concern and encouragement from others to engage in health promoting behaviours, including medication adherence, may combine with social desirability needs on the part of the patient to yield higher rates of medical co-operation. There is strong evidence that positive social support, including being married, is associated with adherence to ART (Holstad et al, 2006).

Figure 4: Employment status of respondents



The above graph is illustrates the following:

Employment status of respondents

Employed Zwelitsha 35% Dimbaza 18%

Unemployed Zwelitsha 65% Dimbaza 82%

Conversely, in a qualitative study of HIV positive women participants reported that ruptures in positive social support such as the death of a spouse, the end of an intimate relationship and family conflict resulted in some questioning their need to adhere to medication (Wood, Tobias & McCree, 2004).

Sub-Themes that emerge

- All patients need to be treated with respect,
- Nutritional problems were a common barrier to patient adherence to medication,
- Food security is a pre-requisite for the initiation, as well as the continuation of the treatment.

4.3. THE FINDINGS IN RELATION TO THE LENGTH OF TIME THE PATIENT HAS BEEN ON ART

According to the findings from quantitative research, the length of time patients have been on ART has a bearing on their adherence to ART. From the patients who participated, 52% had more than 12 months taking ARV treatment. It is also important to note that the percentage of those who had more than 12 months taking ARV treatment have also been attached to a Patient Advocate on accessing ART medication.

Table 6: The length of time the patient has been on ART has an influence on ART adherence

Length of time on treatment (n=37)

Treatment months	**Combined**	**Zwelitsha**	**Dimbaza**
0 – 6 months	4 (11%)	4	0
7 – 11 months	14 (38%)	10	4
12- 23 months	10 (27%)	5	5
24 months and over	9 (24%)	1	8
Total	**37 (100%)**	**20 (100%)**	**17 (100%)**

The qualitative findings did not support these findings. The length of time the patient has been on ART had no bearing on ART adherence. Healthcare workers who participated in the semi-structured interviews, 80% were having more than three years experience working in the ARV unit. They agreed that the length of time patient has been on ART has no bearing on adherence. The longer the period the patient is on highly active antiretroviral therapy (HAART), the greater the chances of non-adherence. Many patients when they feel physically fit begin to relax and not stick to their regimen.

The Health Care Workers (HCW) 20%, believe that adherence is totally unpredictable and the issue of adherence remains a major problem in ARV settings.
These findings are disputed by Cambiano (2010) in the Royal Free Clinic cohort, where they studied long term trends in adherence to antiretroviral therapy. The aim was to investigate long term trends in highly active antiretroviral therapy (HAART) adherence to identify the main predictors and to evaluate whether participants experience periods of low adherence (≤ 60%). The findings were that as measured by drug coverage, does not decrease on average over more than a decade from start of HAART.

4.4. FINDINGS RELATED TO MISSING CLINIC VISITS IN THE LAST 3 MONTHS

Table 7: Missing clinic visits in the last 3 months

Missing clinic visits	Combined n=37	Zwelitsha n=20	Dimbaza n=17
Yes	13	7	6
No	24	13	11

The above table illustrate the quantitative findings of respondents who missed going to the clinic in the last three months. Various reasons for missing clinic appointments were cited.

Table 8: Reasons for missing

Reason	Zwelitsha n=20	Dimbaza n=17
Very sick	1 (5%)	1 (6%)
Had no transport	0	1 (6%)
Family problems	3 (15%)	2 (12%)
Had to work	2 (10%)	1 (6%)

Did not check date right	0	1 (6%)
Was not at home	1 (5%)	0
Total	**7 (35%)**	**6 (32%)**

The above table illustrate various reasons cited by respondents for missing clinic appointments in the last 3 months. The response rate in Zwelitsha was 35% of those who answered yes to missing clinic appointment and 15% for those who missed because of family problems. The response rate in Dimbaza was 32% for those who answered yes to missing clinic appointments and 12% of those who missed due to family problems. It is important to note that regular clinical attendance for medication refills and optimal adherence to ART has a critical influence on outcomes of ART. Continuity of care is essential to ensure the maximum health benefits.

4.5. THE FINDINGS RELATED TO FORMS OF SOCIAL SUPPORT AVAILABLE TO PATIENTS AND THEIR NEEDS

Table 9: Needs of respondents

Needs or problems experienced	**Combined n=37**	**Zwelitsha n=20**	**Dimbaza n=17**
Disability grant	7 (19%)	4 (20%)	3 (18%)
Emotional problems	10 (27%)	4 (20%)	6 (35%)
Sexual problems	1 (5%)	1 (5%)	0
Relationship problems	1 (5%)	1 (6%)	2 (5, 4%)
Alcohol problems	7 (19%)	5 (25%)	2 (12%)
stigmatization	5 (13, 5%)	3 (15%)	2 (12%)
Terminal care	0	0	0
Other	4 (11%)	2 (10%)	2 (12%)

The above table illustrates the needs or problems experienced by respondents since receiving antiretroviral therapy. On disability grant, the combined sites, the need was 7 (19%), the percentage seems very low when taking into account the number of patients who are HIV

infected and who are in need of a disability grants. The respondents, 10 (27%) had emotional problems and 7 (19%) had alcohol problems. It is important to note that a number of health care workers when interviewed mentioned disability grant, support and counselling as the priority needs of the patients.

Table 10: Food insecurity influences adherence negative

Respondent	**Verbatim interview quote from the research interview**
Patient advocate	"Patients need to be treated with dignity. But mostly they want to receive social/disability grant, and food parcels".
Professional nurse 1	"They need social assistance in terms of grants for qualifying clients, they need support in a form nutritional soups and bread while waiting to be attended in proper waiting areas".
Professional nurse 2	**"**They receive educational talks, or ongoing counselling, they need money generating projects, as most of them are unemployed"
Professional nurse 3	"Grant is available to those that qualify for it. They need soup kitchens and how to plant vegetables".

The above research findings are supported by the following literature:

A study was conducted in Mbarara and Kampala in Uganda to understand how food insecurity interfered with ARV therapy regimens. Few mechanisms emerged on how food insecurity is common and an important barrier to accessing medical care and ARV adherence. ARV increased appetite and led to intolerable hunger in the absence of food. Side effects of ARV were exacerbated in the absence of food. Food insecurity can contribute to ARV non-adherence and treatment interruptions or to postponing ARV initiation (Sheri, Weiser, Tuller et al, 2010).

The impact of HIV infection and associated complications on overall nutritional status has been identified from the early stages of the epidemic. The spread of HIV through many regions of the world is highlighting the complex and evolving relationship between food, HIV infection and nutritional status for people with HIV and people who are most vulnerable to HIV. Nutritional interventions can improve health outcomes and are an integral part of HIV care at any stage of disease and throughout the lifecycle.

It is well understood that poor nutritional status has a detrimental effect on immune system development and function. Similarly, declining function, as is experienced in HIV infection, has a direct and indirect impact on nutritional status.

4.6. FINDINGS RELATED TO WHAT MOTIVATES PATIENTS WHO CONTINUE TAKING THEIR ANTIRETROVIRAL MEDICATION?

The researcher is aware that various factors may motivate patients to continue taking antiretroviral medication. Patients may require emotional support to continue their treatment both from their family and HIV positive peers. Feeling better, prospects of living longer, family support, information about ART, support for income generating activities, disclosure of HIV status, prayer and transport, all are factors that may motivate some patients (Igumbor, et al, 2007).

Table 11: Motivation for taking ARV medication

Motivation	Frequency	Percentage
Survival	13	35
To gain strength	15	41
Children	5	14
Doctor	2	5, 4
Family support	2	5, 4
Encouragement	0	0
Other	0	0
Total	37	100%

Various options were asked of respondents to indicate what motivates them to continue taking antiretroviral medication.

The above data show that patients are taking their treatment because they want to gain strength (41%), and 35% are taking their treatment because they believe they want to survive. The 14% would do so because of their children, and only 5,4% are doing it for their family and the doctor.

The research findings of the qualitative part of the research also answer the question on what motivates patients who continue taking their ART treatment. The data collected from the qualitative part revealed the following:

Sub-Themes

- Viral suppression has an effect on general well being,
- Family support and insight on the disease has an influence ART adherence,
- Ongoing counselling sessions has an influence on ART adherence.

Table 12: Motivation for patients to continue taking treatment

Respondent	**Verbatim interview quote from the research interview**
Professional Nurse 2	"They tend to be motivated to take treatment when there is viral suppression and general wellbeing is improved".
Professional Nurse 3	"Family support is vital and patients have more insight when the information has been made clear to them".
Patient Facilitator	"In many instances sickness and death of family members motivates them to adhere to medication".

The above research findings are supported by the following literature:

A striking finding in the study conducted in Sub-Saharan Africa was that patients' feeling of improved health could be a barrier as well as a facilitator to adherence. Patients were said not to continue taking their medication when they felt better. The stage of treatment when patients are starting to feel better could be a critical turning point with regards to adherence. Patient report being less adherent to regimens when they begin to feel better or when they report losing faith in the health information they receive leading to decreased perception of the severity of the disease (Mills, Nachega, Bangsberg et al, 2006).

4.7. FINDINGS RELATED TO DIFFICULTIES EXPERIENCED BY PARTICIPANTS AS A RESULT OF ART MEDICATION

Table 13: Difficulties experienced with ART as reported by respondents

Difficulties experienced on	Never	Rarely	Often	Always

ART				
Side effects	16%	62%	19%	0
Clinic visits	32%	11%	2, 7%	0
Appetite	19%	59, 4%	19%	0
Taking pills	65%	0	2, 7%	0
Finance	19%	19%	49%	11%
Difficulties at work	89%	5, 4%	0	0
Support group	92%	5, 4%	2, 7%	0
Place to stay	92%	0	5, 4%	0

The above data related to a multi-answer questionnaire. The respondents indicated more than one problem in response to the question. There were mixed responses to the question. On finance, 49% of respondents reported to often experiencing financial difficulties. The question on difficulties at work, 89% of respondents reported to have never experienced any difficulties as many respondents were unemployed.

The research findings on the qualitative part of the research revealed the following:

Theme

Patients experience various difficulties with regards to ART medication

Sub-Themes:

- Side effects can be a barrier to ART adherence,
- Employment issues can be a barrier to ART adherence,
- Stigma and disclosure are a barrier to ART adherence,
- Financial problems influence adherence to ART.

Table 14: Patients experience various difficulties with regards to ART medication

Respondent	Verbatim interview quote from the research interview
Professional Nurse 1	"Work related problems; some are not being given permission to collect their treatment on scheduled dates and times".
Patient Advocate	"Fear of side effects and to be seen in ART centres".
Professional Nurse 2	"Disclosure is still a barrier and has resulted in non-compliance".
Pharmacy Assistant	"Some still nurse problems with alcohol abuse causing them to forget about taking treatment"

4.8. FINDINGS RELATED TO IMPROVEMENT IN QUALITY OF LIFE SINCE TAKING ANTIRETROVIRAL MEDICATION

Table 15: Improvement in quality of life since taking antiretroviral

Improvement in quality of life	Frequency	Percentage
Gaining strength	20	54
Regaining lost roles	9	24
Taking control	4	11
Rejection or loss	1	2,7
Report physical abuse	0	0
Report emotional abuse	1	2,7
Report stigmatisation	2	5,4
Experience AIDS related symptoms	0	0
Total	**37**	**100**

The above data is related to the quality of life the respondents experienced since taking antiretroviral medication. The improvement in the quality of life vary between gaining physical strength 20 (54%), regaining lost roles or doing whatever activities you were not able to do before 10 (27%) and 4 (10,8%) able to take control of their lives. This is an indication that ART generally improves the quality of life of respondents.

The above research findings are supported by the following literature:

A supportive social network is essential for those living with HIV/AIDS, social functioning and quality of life amidst the stigma of living with HIV in South Africa may be a concern and require further investigation. According Smith et al, (2003), perception of Health Related Quality Of Life (HRQOL) varied in population with HIV infection or AIDS. On most HRQOL measures, low CD4 a count was associated with lower health-related quality of life. Measurement of HRQOL can assist in understanding the long term effects of disease and treatment on persons with HIV.

4.9. FINDINGS RELATED TO ASSISTANCE RESPONDENTS RECEIVED WITH ART ADHERENCE

The question was intended to explore the support system as perceived by the respondents. As defined in chapter three, social support is a network of family, friends, neighbours and community members who are available in times of need. Having people in one's life during a stressful episode from whom one receives emotional, informational, and/or tangible support is a major factor mediating such outcomes. It is assumed that individuals who have access to resources such as social support are more likely to be effective in managing stressful situations and less likely to experience poor outcomes. Conversely, those who lack in resources such as social support are less able to manage the situation effectively, and thus are more likely to experience negative outcomes (Lazarus & Folkman, 1984).

Table 16: Assistance received with ART adherence

Assistance with ART adherence	**Frequency**	**Percentage**
Family	14	38
No assistance	0	0
Friends	12	32,4
Doctor	3	8,1
Employers	0	0
Partner	3	8,1
Other	1	2,7
Total	33	89, 2

The above research results has indicated that patients 14 (38%) rely on their family for support, and 12 (32, 4%) on friends, and 3 (8,1%) rely on a partner.

Living alone and a lack of support have been associated with an increase in sub-optimal adherence (Williams & Friedland, 1997). It is generally accepted that HIV/AIDS patients who are isolated and without support do not cope well with ART. Not living alone, having a partner, social or family support, peer interaction and better physical interactions and relationships are characteristics of patients who achieve optimal adherence (Motashari et al, 1998).

4.10. DISCUSSION

Forty-seven (47) participants including key informants such as professional nurses, pharmacy assistants and patient facilitators and ARV patients were enrolled in this study and interviewed using one of the instruments designed to collect data. The research lays the groundwork for future qualitative studies as well as informing future interventions aimed at improving the role played by the community adherence support workers or patient advocates and improving adherence.

4.10.1 Demographic information

In terms of the socio-demographic information the study population consisted of a better resourced sub-population in Zwelitsha, with a higher level of education and employment status. Educational status, financial status, distance travelled and length of time on treatment had no effect on adherence. Dimbaza a poorer sub-population, had lower educational levels and higher unemployment levels (Table 2 and Figure 4). Literacy was significantly associated with lower medication adherence. Verbal instructions to patients who are illiterate seem equally effective as written instructions which are given to all patients (Cauldbeck et al, 2009). The interest of this group was taken care of by the Xhosa translated version of the questionnaire during the study.

The study population was predominantly female (59,4%) and young adults 36-49 year age group (Figure 3). The implication of a higher percentage of respondents being single (35%) has an effect on the burden especially women as they strive to care for their children while the quality of life is being compromised by HIV/AIDS infection. It is difficult to explain the preponderance of females accessing ART services except that generally women have greater

access to HIV testing through routine antenatal services (Equinet/Oxfam, 2004). Since the study did not particularly ask how the particular individuals were screened, this was unlikely to be a major source of referral for women to these clinics. To date, more women than men have accessed treatment, "Women are often more likely than men to attend health services because of dedicated provision of reproductive and child health clinics" (Braitstein et al p53: 2008).

The findings in relation to the level of education, grade 11 or below for Dimbaza was 82% and 65% for the two sites combined. The unemployment figure was 82% for Dimbaza and 65% for Zwelitsha which is a significant finding. Since many of them were unemployed, they are likely, therefore to be able to finance their movement to the clinic or the health centre for treatment. Studies already conducted in Africa reveal that the cost of medication is one of the most significant barriers to treatment adherence (Weiser et al, 2003). Socio-economic barriers have a negative effect on medication adherence. As indicated earlier in this chapter because of poor financial resources, food required to be taken alongside medication may not be easily affordable. It is important to note that one of the roles of the patient advocate is to provide HIV/AIDS related health education and promotion activities. This includes health education on the importance of growing food gardens for the whole family. They are also able to help patients and family to identify needs and may refer to correct resources.

Research indicated that 17 (46%) of respondents were married and 13 (35%) were single and 4 (11%) were divorced (Table 4). These results are for both sites combined. The results may be insignificant as the difference between single and married respondents is not significant. The results may explain the challenges faced by patients who may be reluctant to disclose their HIV status since people who are in stable relationships will have difficulties disclosing their status.

4.10.2. Length of time patient on ART

The findings in relation to the length of time the patient has been on ART had an important bearing on how respondents view the support received from the community adherence treatment supporter also known as the patient advocate (PA). On initiation of ART treatment, patients are immediately attached to a patient advocate. They make an agreement together whether they would like to be visited at home or would like to be seen at the facility. This is done so as to identify problems within the client's household which could negatively affect

treatment adherence. It is important to note that 51 % of respondents had only been on ART for 11 to over 24 months (Table 6). As a result the issue, which patients currently face in these settings may not be same as those faced by people who have been on therapy for a longer time. It was found that the duration of treatment greater than two years was associated with increased non-adherence to ART (Andreo et al, 2001). It is likely that the results of follow up study would deviate from the current findings as people face treatment fatigue. Both facilities involved in the study had 1st and 2nd line treatment regimens according to the South African National Guidelines.

4.10.3. Needs and Problems

The needs and problems of respondents ranged from disability grants, emotional problems, alcohol problems and interestingly there were 4 (11%) of respondents who responded other as an indicator, and all indicated that they really had no problems since starting ART therapy (Table 9). Health Care Workers (HCW) mentioned needs such as disability grants, some on-going counselling which was in agreement to what the respondents' needs were in terms of emotional needs (Table 10). Patient advocates are not trained counsellors but due to staff shortages they always fulfil that role.

4.10.4. Motivation of patients to continue ART

The question on what motivates respondents to continue taking their antiretroviral therapy, was asked to gain insight on what motivates patients to continue taking ARV medication. The findings were that 15 (41%) respondents would like to gain strength and 13 (35%) were motivated to survive (Table 15). These are significant findings as patients want to experience a better health, to live longer and patients generally appreciated the positive effects of ART and were encouraged to continue treatment (Sanjobo et al, 2008). The findings by Mills et al, (2006) that when the patient starts feeling better becomes less adherent, is a critical turning point with regards to adherence and an important point that needs to be followed up. This is where the work of the patient advocate would play an important role. Patient advocates stay in the same areas as the patient and also speaks and understand the language spoken by the patient.

4.10.5. Barriers to ART adherence

Respondents experienced barriers that ranged from financial constraints, side effects and appetite. The question wanted respondents to answer to frequencies of never, rarely, often

and always. Financial constraints were a barrier that was significant at 49% often and 11% always. Unless programmes are designed to provide food assistance in the first months of ART, optimal adherence is going to be difficult to achieve.

The critical issue is training of adherence counsellors, community sensitization and home-based care services. Patient advocates assist by following up on clients to promote adherence and address issues as they arise.

Side effects and appetite were at 19% often occurrences (Table13). Some patients never experienced side effects. For ART to achieve viral suppression combined treatments with at least three ARVs is needed. The important finding was the 92% never experienced difficulties with support groups while emotional problem was 11% among the highest needs of the respondents. It is important to note the despondency of some patients with regard to forming or joining support groups because of fear of disclosure. There are barriers to ART adherence that are related to patient-provider dialogue. Insufficient time by medical doctors to assess or discuss patient needs and make referrals to nurses or counsellors may be the cause of this barrier to adherence in some sites. Barrier to adherence also include patients' lifestyle and social habits, e.g. alcohol abuse and some patient routines like travelling. Patients' beliefs about HIV/ART and its effectiveness may hamper facilitation of ART adherence. Inadequate knowledge and negative beliefs about HIV disease and treatment effectiveness present an important barrier to ART adherence.

4.10.6. Assistance respondents receive with ART adherence

The findings on the assistance respondents receive with ART adherence once again, indicate the importance of family support 14 (38%), and 12 (32,4%) rely on friends for support (Table 16). Supportive family members or friends can help remind patients to take their medication and assist with management of adverse effects. Good support both practical and emotional has been shown to be an important factor in maintaining ART adherence. However in order to receive direct social support, people must disclose their HIV-positive status to other, as greater disclosure predicts social support. Disclosure though can also lead to stigma and discrimination.

Chapter 5: Conclusion and recommendations

5.1. CONCLUSIONS

The study was both quantitative and qualitative. The qualitative data provide in-depth insight into people's experiences with ARV. The study used the opinions of 37 women and 10 health care workers and it has not been conclusive. The results of this research paper could not conclusively answer the research question of the relationship between the levels of support given by patient advocates and adherence to ART treatment.

The strength of this study lies in the qualitative data in which we present views about adherence by reporting statements from the health care workers. South Africa has made a good start in scaling up ART and this is widely appreciated. We anticipate that as ART rollout continued in South Africa, patient advocates can also be increased in numbers to serve a larger community. Training of adherence counsellors and community sensitization is very important going forward. Continuity of care is essential to ensure the maximum health benefits of ART. Addressing food insecurity as part of emerging ARV treatment programs is critical for their long term success.

5.2. RECOMMENDATIONS

The result of this research of this research could not conclusively answer the question of the relationship between the level of support given by the patient advocate and ART adherence. Therefore the following recommendation is made:

Improved training of patient advocates and improving their numbers and more putting emphasis on the work they do, training more adherence counsellors, sensitizing the community on the availability of treatment and the importance of adherence. Home-based care programmes done by various community volunteers, social support provided at community and family levels must be strengthened.

Enhancing the psychological make-up of the care-giver is of importance as continued education for illiterate attendants and counselling might help improve adherence.

HIV awareness and prevention campaigns should be intensified, and the number and distribution of voluntary testing centres should be increased. Efforts to prevent AIDS-related

stigma and discrimination should be strengthened. Collaboration with non-governmental organisations (NGOs) and the establishment of a referral network should be feasible within the resource constraints of the health care system.

The capacity of poor families to cope with HIV/AIDS must be strengthened through implementation of income generating schemes and harmonisation of the work rendered by non-governmental organisations. It is important for government to address the ambiguities around the administration and distribution of disability grants. Addressing food insecurity as part of emerging ARV treatment programs is critical for the long term success.

5.3. STUDY LIMITATIONS

The study did not document the association between social support, ART adherence, using patients' records as this was not within the scope of the study to use patients' record and interpret them. The study was limited by time and finance, and only a small sample was selected as representative of the affected population. The study relied on the honesty of the respondents to provide accurate and authentic information. Future studies should also examine an alternative perspective on the patient-provider relationship.

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APPENDIX A

STELLENBOSCH UNIVERSITY

Africa Centre for HIV/AIDS Management

Questionnaire

November 2010

Assignment submitted in partial fulfilment of the requirement for the degree of Master of Philosophy (HIV/AIDS Management) at Stellenbosch University

STUDY LEADER: Mr Gary Eva

Nov 2010

Date……..

Name of Clinic……..

PLEASE ANSWER THE FOLLOWING QUESTIONS BY CROSSING (X) THE RELEVANT BLOCK OR WRITING DOWN YOUR ANSWER IN THE SPACE PROVIDED.

Example: of how to complete this questionnaire:

Your gender?

If you are female:

Male 1 **Female** 2 x	

Section A- Background information

1.

Gender

Male	1
Female	2

2. Age (in complete years)

3. What is your marital status?

Single	1
Married	2
Separated	3
Widowed	4
Divorced	5
Cohabiting	6

4. How would you describe your economic status?

Poor	1
Below average	2
Average	3
Above average	4
Affluent	5

5. Your highest educational qualification?

Grade 11 or lower (std 9 or lower)	1
Grade 12 (Matric,std 10)	2
Post-Matric Diploma or certificate	3
Baccalaureate Degree(s)	4
Post-Graduate Degree(s)	5

6. How would you describe the area in which you reside?

Urban	1
Rural	2

7. How would you describe the status of your employment?

Full time	1
Part time	2
Contract	3
Casual or temporary	4
Unemployed	5

Section B – General Health

8. In general, how would you describe your health?

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

9. Have you told anyone that you are HIV Positive?

Yes	1
No	2

10. Whom did you first tell that you are HIV Positive?

Father	1
mother	2
sister	3
brother	4
grandmother	5
grandfather	6
aunt	7
uncle	8
partner	9
other	10

Specify…….

11. How long have you been on antiretroviral treatment (ART)?

0 - 6 months	1
7 - 11 months	2
12 – 23 months	3

SECTION C

Like most people it is likely that you have missed taking your antiretroviral medication at some point in time. In order to improve the adherence support that patients are getting, we would like to ask you questions about how often you have missed taking your antiretroviral pills.

12. How long does it usually take you to travel from your home to the clinic?

Minutes or hours……..

13. In the last 3 months, have you ever feel put off going to the clinic or hospital?

Yes	1
No	2

14. Could you tell why you put off going to the clinic or the hospital in the last 3 month?

I was too sick	1
I did not have enough money for transport	2
Transport was not available	3
I had family obligations	4
I did not have anyone to accompany me	5
I had to work	6
Other	**7**

Specify**……**

15. During the last seven (7) days, how many times in total did you take one or more of your antiretroviral pills more than two (2) hours late?

		Times

16. Why did you miss a dose?

Family said no to medication	1
I was away from home	2
Forgot, I was busy	3
Did not understand instruction	4
Unable to care for self	5
I feared side effects	6
I felt better	7
I did not want other to see	8
Other	9

Specify……..

17. Please rank in order of importance each of these forms of support and aids you use to increase adherence to ART medication? Use each of the numbers 1 to 8 only once.

No support	
Treatment Buddy	
Pill count	
Diary chart	
Electronic device	
Pill box	
Cell phone	
Clock Watch	

18. How would you rate your adherence over the last month?

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Very Poor	6

SECTION D

Cross (x) the relevant block

19. We would like to know whether or not you experienced any difficulties regarding taking ART medication.

	Never	Rarely	Often	Always
Experienced some side effects	1	2	3	4
Visits to the Clinic	1	2	3	4
Experienced problems with appetite	1	2	3	4
Experienced problem taking your pills	1	2	3	4
Experiencing problems with money	1	2	3	4
Experienced problems at work	1	2	3	4
Experienced problems joining a support group	1	2	3	4
Experienced a problem with no place to stay	1	2	3	4

20. We would like to know what has been your motivation to continue taking antiretroviral pills.

Survival	1
To gain strength	2
children	3
Doctor	4
Family support	5
encouragement	6
other	7

Specify……

21. We would like to know whether or not you received any assistance with ART adherence from;

Family	1
Patient advocates	2
No assistance	3
Friends	4
Doctor	5
Employers	6
Partner	7
Other	8

Specify……..

22. We would like to know whether or not you had needs or problems since receiving ART

Disability grant	1
Emotional problems	2
Sexual problems	3
Relationship problems	4
Alcohol problems	5
Stigmatization	6
Terminal care	7
Other	8

Specify…….

23. We would like to know how best to describe your emotions with regards to your experience of illness and your reaction to it

X Cross the answer that best describe your feeling.

	0 - 6months	7 – 11 months	12 – 23 months	24 months and over
Acceptance	1	2	3	4
Positive	1	2	3	4
Gratefulness	1	2	3	4
Mixed feelings	1	2	3	4
Depression	1	2	3	4

24. We would like to know whether or not there was an improvement in quality of life since taking antiretroviral medication.

Gaining physical strength	1
Regaining lost roles	2
Taking control	3
Rejection or loss	4
Report physical abuse	5
Report emotional abuse	6
Report stigmatisation	7
Experience AIDS related symptoms	8

Thank you for your HELP!

APPENDIX B

RESEARCH QUESTIONNAIRE

UMHLA: ……

IGAMA LEKLINIKI: ……..

NCEDA PHENDULA LE MIBUZO ILANDELAYO NGOKUSEBENZISA U (X) KWIBLOKO EFANELEKILEYO

Umzekelo: Wokuba ungayiphendula njani imibuzo:

Ubuni?

Ukuba ungumfazi

Male 1 Female 2 X	

SECTION A – IMIBUZO NGOKUBANZI

1.

Ubuni

Male	1
Female	2

2. Age (Ngokupheleleyo)

3. Ungowaluphi uhlanga

Umnyama	1
Umhlophe	2
Ungowebala	3
UngumNdiya okanye UngumAsIa	4

4. Ithini imo yakho yomtshato?

Anditshatanga	1
Nditshatile	2
Sisohlukene	3
Wasweleka	4
Uqhawuliwe	5
Siyahlalisana	6

5. Ungayichaza njani imeko yakho yezemali?

Poor	1
Below average	2
Average	3
Above average	4
Affluent	5

6. Ngawaphi amabanga aphezulu owaphumeleleyo?

Grade 11 okanye u std 9 okanye ngaphantsi	1
Grade 12 okanye std 10	2
Post-Matric Diploma okanye isetificate	3
Baccalaureate Degree (s)	4
Post- Graduate Degree (s)	5

7. Ungayichaza njani le ndawo uhlala kuyo?

Yidolophi	1

Yilali	2

8. Ingaba Uyasebenza?

Ewe	1
Hayi	2

9. Ukuba ngu Ewe ungayichaza njani indlele osebenza ngayo?

Ngumsebenzi osisigxina	1
Awusosigxina	2
Yikontrakt	3
Ndilikhesele	4

SECTION B – IMPILO YAKHO NGOKUBANZI

10. Ungayichaza njani imeko yempilo yakho?

Ndiphile qethe	1
Ndiphilile kakhulu	2
Ndiphilile	3
Ndiphilile kancinci	4
Andiphilanga	5

11. Ukhona umntu omxeleleyo ukuba unentsholongwane kagawulayo?

Ewe	1
Hayi	2

12. Uxelele bani kuqala ukuba unentsholongwane kagawulayo?

Utata	1
Umama	2
Udade	3
Umnakwethu	4
Umakhulu	5
Utamkhulu	6
UAnti	7
Umalume	8
Umlingane	9
Abanye	10

Cacisa……..

13. Lixesha elingakanani usebenzisa ipilisi zokuthomalalisa intsholongwane kagawulayo?

0 – 6 iinyanga	1
7 – 11 iinyanga	2
12 – 23 iinyanga	3
24 iinyanga nangaphezulu	4

SECTION C.

Njengabantu bonke kungenzeka ukuba ukhe ulibale ukusela ipilisi zakho ngamaxesha athile. Ukuze siphucule uncedo esilunikeza izigulana malunga nokusela ngendlela eyiyo ipilisi, ndicela ukukubuza imibuzo ngokuba kukangaphi ulibala ukusela ipilisi zakho zokuthomalalisa intsholongwane kagawulayo.

14. Kukuthatha ixesha elingakanani ukuhamba usiya ekliniki?

Imizuzu okanye iiyure……

15. Kwezi nyanga zintathu zidlulileyo ukhe wakuphosa ukuya ekliniki okanye esibhedlele.

Ewe	1
Hayi	2

16. Ungachaza ukuba yintoni eyabangela okokuba ungayi ekliniki okanye esibhedlele kwezi nyanga zintathu zidlulileyo.

Ndandigula kakhulu	1
Ndandingenayo imali yetransport	2
Itransport yayingekho	3
Ndandinengxaki zosapho	4
Ndandingenamntu wokundikhapha	5
Kwakufuneka ndiphangele	6
Ezinye	7

Cacisa……

17. Kwezi ntsuku zisixhenxe (7) zidlulileyo kukangaphi apho usela ipilisi zokuthomalalisa ugawulayo emva kweyure ezimbini nangaphezulu, ipilisi enye okanye nangaphezulu?

Times

18. Kutheni uze uphose ukusela iipilisi?

Usapho lwathi mandiziyeke ipilisi	1
Bendingekho ekhaya	2
Ndalibala, ndandixakekile	3
Zange ndiyiqonde imiyalelo	4
Ndandingakwazi ukuzenzela	5
Ndandisoyika iside effects	6
Ndaziva ndibhetele	7

Ndandingafuni kubonwa ngabanye	8
Enye	9

Cacisa……

19. Nceda dwelisa ngokubaluleka kwazo ezi zinto zikuncedisa ukukhumbula ukusela ipilisi zakho zokuthomalalisa intsholongwane. Dwelisa ukusuka ku 1 uye ku 8.

Akukho luncedo	
Treatment buddy	
Ukubala Ipilisi	
Diary chart	
ielectronic device	
Ipill box	
Icellphone	
Iclock watch	

20. Ungayichaza uthini indlela otya ngayo ipilisi zakho?

Ngokubalaseleyo (excellent)	1
Kakuhle kakhulu(very good)	2
Kakuhle (good)	3
Ndiphakathi (fair)	4
Kakubi (Poor)	5
Kakubi kakhulu (very poor)	6

SECTION D

Nqamleza (X) ibloko eyiyo

21. Sifuna ukwazi ukuba ukhe wafumana ingxaki ukutya ipilisi zakho zokuthomalalisa intsholongwane kagawulayo?

	Zange	Kambalwa	Kaninzana	Okokoko
Ndaba nazo iside effects	1	2	3	4

Ukuya ekliniki	1	2	3	4
Ingxaki zokunganqweneli ukudla	1	2	3	4
Ingxaki zokusela iipilisi	1	2	3	4
Ingxaki zemali	1	2	3	4
Ingxaki zasemsebenzini	1	2	3	4
Ingxaki zokungenela isupport groups	1	2	3	4
Ingxaki yokungabi nandawo yokuhlala	1	2	3	4

22. Sifuna ukwazi okokuba yintoni ebikukhuthaza uqhubeke uzisele ipilisi zakho zokuthomalalisa intsholongwane kagawulayo?

Ukuphila	1
Ukuba namandla	2
Abantwana	3
Ugqirha	4
Inkuthazo yosapho	5
Ukukhuthazwa	6
Ezinye	7

Cacisa……
…….

23. Sifuna ukwazi ukuba lukhona na uncedo okhe walufumana malunga nendlela yokusela ipilisi zakho zokuthomalalisa intsholongwane kagawulayo kwi;

Kusapho	1
Ku Patient advocate	2
Akukho ncedo ndilufumeneyo	3
Kubahlobo	4

Kugqirha	5
Kumqeshi	6
Kumlingane	7
Kwabanye	8

Cacisa……
……..

24. Sifuna ukwazi ukuba ubunazo na iimfuno okanye iingxaki okoko wathi watya ipilisi zentsholongwane kagawulayo?

Igranti yokugula	1
Unxunguphalo ngokwasemphefumlweni	2
Ingxaki zesondo	3
Ingxaki zothando	4
Ingxaki zotywala	5
Ukubekwa ibala	6
Zokucinga kokuphela kobom	7
Ezinye	8

Cacisa……
……..

25. Sifuna ukwazi ukuba ungazichaza kanjani ingcinga zakho ngokubhekiselele kumava akho okugula nendlela owaziphatha ngayo.

Xabela impendulo echaza bhetele iingcamango zakho

	0 – 6 iinyanga	7 – 11 iinyanga	12 – 23 iinyanga	24 iinyanga nangaphezulu
Ukwamkela	1	2	3	4
Ukuthatha kakuhle izinto	1	2	3	4

Ukuba nombulelo	1	2	3	4
Ukuba nengcinga ezibethabethanayo	1	2	3	4
Ukugula ngoba ucinga nzulu(depression)	1	2	3	4

26. Sifuna ukwazi ukuba kwabakhona na umahluko kwindlela ubomi bakho obuyiyo emva kokuba usebenzise iipilisi zentsholongwane kagawulayo.

Ndafumana amandla	1
Ndenza izinto ebendingasakwazi ukuzenza	2
Ndathathela kum ubomi bam	3
Ukulahlwa nokulahlekelwa	4
Ndachaza ngokuhlukunyezwa ngokwasemzimbeni	5
Ndachaza ngokuhlukunyezwa ngokwasengqondweni	6
Ndachaza ngokubekwa ibala	7
Ndaba nezigulo zokuchatshazelwa ngugawulayo	8

ENKOSI NGOKUSINCEDISA KWAKHO!

APPENDIX C

STELLENBOSCH UNIVERSITY
Africa Centre for HIV/AIDS Management
November 2010

INTERVIEW SCHEDULE

Assignment submitted in partial fulfilment of the requirement
for the degree of Master of Philosophy (HIV/AIDS
Management) at Stellenbosch University

STUDY LEADER: **Mr Gary Eva**
November 2010

Today's Date: ……..
Date of birth…….
Sex (circle): Female Male
Occupation…….

1. Do you think the longer the period a patient has been on ART influences adherence?

2. Do you think is there any relationship between marital status, education, residential area or living condition that could influence adherence to antiretroviral therapy**?**

3. What form of social support is available to the patients receiving antiretroviral medication at the clinic? What form of support of support do you think they need?

4. What do you think has been the motivation for patients who continue taking antiretroviral medication?

5. What do you think are experiences of patient taking Highly Active Antiretroviral Therapy (HAART) and barriers to HAART adherence.

6. What do you think are the strengths and weaknesses of using patient advocates/ adherence support workers as adherence supporters?

7. What do you think is the role played by patient advocates in addressing human resource shortage in the health care service?

8. What do you think of the quality of adherence counselling at the clinic?

THANK YOU FOR YOUR HELP!

APPENDIX D

INFORMED CONSENT FORM

You are invited to participate in a study conducted by Nomfundo Kamana as part of a dissertation as an MPhil student (HIV/AIDS Management Centre) at Stellenbosch University.

You were selected to participate in this study as you are part of patients receiving social support from the Patients Advocates. Questions will focus on the perceptions, attitudes and roles of patient advocates as social support structures in antiretroviral treatment adherence. The researcher will use a questionnaire and take notes during the interview.

PURPOSE OF THE STUDY: The purpose of the study is to understand the role of the patient advocate in a clinical and social support structure in antiretroviral treatment adherence.

PROCEDURES: The study will involve answering a questionnaire that will not be longer than 20 minutes. You will answer the questionnaire in the setting most comfortable to you. Questions will focus on the perceptions, attitudes and roles of patient advocates in antiretroviral treatment adherence as social support structures.

POTENTIAL RISKS AND DISCOMFORTS: The study asks about experiences, perceptions, attitudes and feelings that may be unpleasant to recall. This recall may cause some minimal discomfort. The probability and magnitude of discomfort anticipated in the research are not greater than those ordinarily encountered in daily life. There are no risks from your participation in the research.

BENEFITS: You will derive no personal benefits to the study. Your study will benefit others by enabling social scientist to learn about the important role played the Patient Advocate as social support in ART adherence. The information will be used to assist in the development of appropriate services for people who access healthcare services.

PAYMENT FOR PARTICIPATION: There will be no payment for taking part in the research.

CONFIDENTIALITY: All information you supply during the research will be held in confidence and will be disclosed only with your permission. Your name will not appear in any report or publication of the research. Access to research data is limited to the study leader and his dissertation committee. Notes and any other identifying participant information will be kept in a locked cabinet in the personal possession of the researcher. When no longer necessary for research, all materials will be destroyed.

PARTICIPATING AND WITHDRAWAL: Participating in the study is voluntarily. You can stop participating in the study anytime, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researcher. You may refuse to answer any questions you do not want to answer and still remain in the study.

If you decide to withdraw from this study, you should contact Ms Nomfundo Kamana at nomfundokamana@yahoo.co.uk or 0791626796. You can also contact Mr Gary Eva at gev@telkomsa.net or 021-887 8738 who is my study supervisor.

RIGHTS OF RESEARCH SUBJECTS: You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Malenè Fouchè (mfouche@sun.ac.za; 021 80846220 at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by…….. in Xhosa and I am in command of this language or it was satisfactorily translated to me . I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____ _____

Signature of Subject/ Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to……. [name of the subject/participant] and/or [his/her] representative…… [name of the representative]. [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in Xhosa and no translator was used.

_____

_____

SIGNATURE OF INVESTIGATOR

DATE